Riding the Emotional Roller Coaster of Survival

Kauser Ahmed PhD
Psychologist/ Training Director
Simms/Mann – UCLA Center for Integrative Oncology
Goals for Talk

— Understand psychosocial challenges of survivorhood
— Learn skills to manage the impact of stressful triggers
— Define own tools for optimal coping and well-being
The Journey of Survivorship is Defined by Movement

• Not fixed state, but fluid and evolving experience

• Processed differently at different stages of treatment and lifespan

• Marked by both periods of stability/mastery and vulnerability/uncertainty
Long Term Impact of Transplant

• 2/3 of survivors have at least one chronic health condition
• Higher risk of medical problems than other cancer survivors
• Late effects related to fatigue and endocrine, cognitive, sexual functioning

All of these have significant psychological implications

Sun et al Bone Marrow Transplant Study 2010
Psychosocial Impact of Transplant

• 20-45% of survivors experience emotional distress
• Up to 20% experience clinical depression, anxiety and symptoms of PTSD
• Less than half of individuals with psychological need receive support
• Emotional distress takes longer than physical distress to resolve—up to 2 years

Mosher et al, Bone Marrow Transplant 2010
Where Does Stress Fit in this Picture?
Stress is a Normal Human Response

• To perception of threat
  • physical: racing heart, sweating palms, fast breathing
  • mental: focus on danger, vigilance
  • emotional: fear, worry, feeling unsafe

• Helpful in short bursts

• NOT helpful as a chronic way of living OR

• When we feel we have no control over what is happening
Transplant Journey: The Challenge

• How do you manage your sense of
  • Threat
  • Danger
  • Anxiety

• When the threat is
  • Not immediate
  • Not imminent
  • Does not pass
  • Becomes chronic
Rebalancing with Stress

Know what it is and when it happens

Accept that it cannot be eliminated, but can be managed

Exercise choices that help you manage your physical, mental and emotional reactions
Triggers for Transplant-Related Stress
Triggers For Stress

• Disruptions in equilibrium brought on by expected or unexpected events

• Late Effects, Symptoms

• Scans, Follow up Appointments

• News from Outside
Strategies with Health Care Team

• Ask for discussion about your follow up care in ways comfortable for you

• Parameters of Care
  • communicate about symptom management
  • Goals of testing

• Develop your “team” for health priorities

higher levels of distress among patients who engaged in high health surveillance without accessing healthcare support.

» Thewes et al. Support Cancer Care 2012
Strategies with Family/Friends

• Talk through the changes and priorities in new normal
• Prepare for good and stressful events
• Focus on relationship, not role function
• Have someone(s) who understands

*Individuals with less social support express greater anxiety and worry*

*Liu et al. Cancer 2011*
Set Realistic Goals for Nutrition and Lifestyle Changes

• Discuss targets for improved changes
• Avoid all or nothing thinking
• Set and commit to realistic goals

Fear during cancer is reduced with higher levels of confidence in ability to engage in healthy behaviors.

News from the Outside

• Practice Choice

• Know your Own Story

• Allow for distress/sadness

• Allow for moving back into your life
Professional Care Needed

• Symptoms of anxiety, sadness or worry that persist several weeks w/o improving

• Symptoms that impact functioning:
  • sleep disturbance
  • trouble concentrating
  • agitation/fatigue

• Symptoms that may be worsened by treatment
Mind / Body / Spirit
Wellbeing
Principles for Well-being: Body

• Relaxing the Body
  • Breathing Meditation
  • Guided Visualization
  • Movement – walking, Qi Gong, yoga

• Getting pain, fatigue, symptoms under control
Principles for Well-being: Mind

Balancing Thoughts and Emotions

• Allow for all feelings, make choices about attitudes

• Mature coping is more than “being positive”
Principles for Wellbeing: Spirit

Engaging the Spirit

• Practice self compassion
• Share the experience
• Locate your sources of strength, comfort meaning and joy
Stress in Context of Transplant Experience

• Stress can’t be eliminated

• Connected to knowledge of vulnerability

• Burden to be managed and....

• Reminder of what is precious
What Am I Doing Right?

• Being proactive about your emotional as well as physical well-being
• Following healthcare recommendations
• Taking the time to learn healthy coping
• Practicing what works for you
Where else can I go for support?

Meditation website

Blood and Marrow Transplant Information Network
www.bmtinfonet.org

National Bone Marrow Transplant Link
www.nbmtlink.org
Additional Resources Available

www.SimmsMannCenter.ucla.edu
Streaming lectures from experts, articles and more